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ABSTRACT

A widespread bias exists among legal, medical, and social service professionals that the appropriate placement for elderly individuals with cognitive impairment (dementia) is a nursing home. Two major reasons for institutionalization are to remove the patient from a potentially harmful situation and to relieve the family of the burden of care. However, research studies have shown little relation between burden and severity of symptoms. Critical factors which account for the differences in the experience of burden are how well the caregiver manages problem behavior, the level of support given to the caregiver, the relationship between the caregiver and the patient, and the quality of the prior relationship. Interventions to improve caregivers' skills in managing the patient and to reduce stress and diminish burden may make home care a viable alternative to the nursing home. Interventions to lower burden include providing information about dementia and its effects on behavior, teaching a problem solving process for managing behavioral impairments, and identifying potential sources of support to relieve the primary caregiver. These interventions can be made through three treatment modalities: (1) one-to-one counseling; (2) family meetings; and (3) support groups. (Each of the intervention techniques and treatment modalities is described in the remainder of the text.) (BL)

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Interventions with Families of Impaired Elderly

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Introduction: Is Community Care Appropriate?

I was recently called to testify as an expert witness in a case, involving a suit against the Public Guardian's office of a California county. The suit alleged that the Public Guardian's office had acted inproperly by placing the defendant in a nursing home, without considering less restrictive alternatives, including continuing to live at home under her husband's supervision. The defense presented by the attorney for the Public Guardian was that someone with senile dementia, as the defendant had, required supervised care in a protected setting, and the appropriate, "least restrictive" placement was indeed a nursing home.

This position reflects a widespread bias, not only in the Public Guardian's office, but among physicians and other professionals who work with elders, that the appropriate placement for someone with cognitive impairment is a nursing home. There is probably no other group for whom institutional care is as likely to be recommended. A majority of caregivers in our clinic report that either their physician, or some other person, has told them they need to place their relative in a nursing home, although most continue providing home care long after the recommendation has been made. As Knight and Lower (1983) have discussed, the issue of whether or not institutionalizaton is appropriate depends on the development of practical criteria for evaluating patients and their circumstances. The question of when institutionalization is appropriate for dementia patients is especially critical, because diagnosis is often viewed as a sufficient reason in itself.

The major reasons for recommending nursing home placement for the dementia patient are to remove the patient from a poor, potentially harmful

situation, and/or to relieve the family of the burden of care. Concerning "harmful situations", the patient living alone is especially at risk, and his/her circumstances are made more difficult because of the limited resources of community-based services to provide a coordinated effort of support. Programs in Great Britain which provide coordinated home services appear somewhat more successful in this respect (Glasscote, Gudeman, & Miles, 1976), but there is no question that the isolated dementia patient in most American communities is not likely to have access to appropriate alternatives to institutionalization.

When there are involved family members, or other supportive persons, that does not guarantee that the care will be adequate, and there will certainly be circumstances when caregivers are abusing the patient, either physically, psychologically, or financially. In these cases, institutional care may again be the only alternative. It is not clear how widespread this kind of abuse is. In our experience, it is relatively rare, but that, of course, reflects the fact that caregivers come to our program seeking help, and have not been identified as needing help by the police or other public agencies. Nonetheless, it should not be assumed that the abuse is untreatable. In the few cases where we have either suspected or had evidence of abuse, interventions with the caregiver have removed that risk. In one case, for example, there was a long history of abuse by the husband of his wife, that pre-dated the onset of cognitive impairment. Clinical interventions at this point, however, were successful in helping him understand her behavior and limitations better, and the abuse stopped.

In the vast majority of cases, the reason for recommending

institutionalization is that the burden of care will become overwhelming for the family, and that it is too difficult to expect to maintain the dementia patient at home. Burden can be defined as the physical, emotional or financial strain caused by caregiving, and by the limitations on the caregiver's personal and social life (Lowenthal, et al., 1967; Zarit, Reever, & Bach-Peterson, 1980; J. Zarit & S. Zarit, 1982). Many people believe that little can be done to relieve the burden of care. They regard burden as due to the severity of cognitive and behavioral symptoms, and since the symptoms are progressive, they assume that burden will be so, as well.

But there is reason to believe that burden does not have a simple linear relation to the severity of symptoms. While there is disagreement on this issue, some studies have found little or no relation between burden and the severity of symptoms as measured by cognitive impairment and the extent of daily problems experienced by the caregiver (Zarit, Reever, & Bach-Peterson, 1980; J. Zarit, 1982). In examining these findings, it becomes apparent that some caregivers report considerable burden, even though their relative has relatively mild deficits, while other caregivers indicate they have little burden, even though they are caring for a patient with severe impairments. Furthermore, in a follow-up study currently in progress, many caregivers still caring for their relative at home are reporting lower levels of burden than when they were first interviewed two years ago. When asked about their situation, they report that certain troubling problems (e.g., wandering, making paranoid accusations) no longer occur, and they no longer get upset over problems they way they used to. A related perspective is the belief that particular behaviors, such as incontinence or waking the caregiver at night, are too stressful for families to manage. Again, however, families vary in

their response to specific deficits. Some do become overwhelmed by incontinence, but others manage it with a combination of skill and humor. As an example of how caregivers respond idiosyncratically to problems, one man whom we have followed in our clinic for several years was overwhelmed early in his wife's illness, when he had to take over the family finances, but later on when she became incontinent, he managed with few difficulties. Many families, of course, do experience increasing burden as the disease progresses, and in an absolute sense, there would be little or no family burden without dementia. But it is important to recognize that families' responses to dementia vary considerably, and the presence of symptoms per se does not indicate overwhelming burden.

The critical question about these observations is why do some caregivers experience intolerable burden while others caring for a patient as impaired report little or no burden. Several factors have emerged from our studies (Zarit, Reever, & Bach-Peterson, 1980; J. Zarit, 1982) which account for some of the differences in the experience of burden. One factor is how well the caregiver manages problem behavior. Some people are overwhelmed by even minor problems, but other caregivers develop positive strategies for managing difficult behaviors. A second factor is the support the caregiver receives. Having some relief from the around-the-clock demands of care is obviously important, although the amount of assistance seems less important than if the caregiver perceives it as adequate. In other words, the quantity of help does not appear as crucial as whether or not the caregiver feels supported by family and other helpers. Third, the relationship between the caregiver and patient affects burden. Husbands, for example, report on the average less burden than wives who are caregivers. The reasons for this finding may have

to do with the fact that husband s generally manage behavior problems somewhat more effectively, and are more likely to use formal social services (J. Zarit, 1982). Another factor related to burden is the quality of the prior relationship, with caregivers who report having had a more positive relationship in the past to the patient having lower burden.

Overall, these findings suggest that the dementia patient's symptoms create the context in which family caregivers can experience burden, but there is a great deal of individual variation in the extent to which burden is manifested. One implication is that one cannot consider institutionalization (or for that matter, home care) appropriate based only on an assessment of the severity of symptoms. Another is that since caregivers vary in their response to patients with dementia, interventions to improve caregiver's skills in managing the patient and the stress on themselves may be effective in diminishing burden, thereby making home care a viable alternative for longer periods of time.

Interventions to Lower Burden

It is inappropriate to consider home care as an alternative to institutionalization, unless assistance is available for family caregivers. The American experience with de-institutionalization has been the closing of the state mental hospitals. While de-institutionalization was begun with considerable idealism, it has largely been a failure, at least partly because community services are chronically underfunded for the numbers of persons they need to serve. De-institutionalization has meant moving patients from situations where they received at least minimal care, and instead, shifting

the burden of care to the family or community without sufficient support. A movement to keep dementia patients out of nursing homes would be equally disastrous, unless accompanied by the appropriate kinds of assistance for caregivers.

Building on clinical experience and the studies of burden which were reviewed earlier, we have developed a program of interventions designed to lower the burden experienced by caregivers of dementia patients. Three intervention techniques are used: 1) providing information about dementia and its effects on behavior; 2) teaching a problem-solving process for managing behavioral impairments; and 3) identifying potential sources of support to relieve the primary caregiver. These interventions are made in three treatment modalities: 1) one to one counseling; 2) family meetings; and 3) support groups. The impact of this program for reducing burden and delaying or preventing institutionalization is currently being evaluated. Each of the intervention techniques and modalities are described below.

Intervention Techniques

Information. The technique of providing information assumes that it is important for caregivers to have as much understanding as possible about their relative's illness and its impact on behavior. Questions that families raise about the disease usually concern the causes and possible cures. Correcting misunderstandings can be important. In one family, for example, the daughters of a patient blamed their father for having caused the disease by having led a reclusive, and self-centered existence, and not attending to their mother's needs. It was only after this belief was corrected that they were able to

give their father and mother support. The question of cures is especially important. Family members may expect that the patient's behavior will improve, if they only find the right combination of drugs, vitamins, or psychological encouragement. While it is important for them to hold onto some hope, they also need to be directed toward making changes that will make the immediate situation more bearable. We encourage families to seek continued treatment, when they are interested in doing so, and the proposed treatment is not likely to make matters worse, but we also stress that the treatment is an experiment, so that they do not have overly high expectations.

The other important type of information concerns explaining why patients behave the way they do. Many problems can be helped by giving the family clear explanations of why they occur. Perhaps the most common complaint of caregivers is that the patient engages in repetitive behaviors, especially asking the same question over and over again. Families sometimes believe the patient does this on purpose or just to get attention, and they are very angry or upset. Pointing out that the person may not remember the answer, or even having asked the question before, may help the family respond differently, such as by being tolerant of the problem. Other problems which families often misinterpret and where correct information is helpful include: when the patient denies having memory loss, when the patient resists attempts to encourage or train memory, when the patient makes accusations that someone is stealing items, and lowered inhibitions. The information provided in each case involves reframing the behavior, so the family can understand what the world must be like to someone with an impaired memory.

Problem-solving. Problem-solving is a process of collaboration between

the caregiver and counselor to determine to what extent problem behaviors can be modified. The first and most important step in problem-solving is assessment. Caregivers are encouraged to keep daily records of when problems occur and what antecedents and consequences there are, that is, what happened before and after the problem. This type of assessment often reveals the cause of the problem and/or potential solutions. A common example of how record-keeping helps is when it is observed that the patient who is not sleeping at night is napping or inactive during the day. The solution, then, is to increase daytime activities. When an intervention, such as increasing activities, is introduced, the caregiver will continue to keep records to evaluate how effective the intervention is. In our experience, behavioral interventions sometimes will not get rid of a problem altogether, but may lower its frequency. By keeping records, the caregiver will see there has been some positive change, even though the problem still occurs.

We encourage caregivers to view problem-solving as a process. Rather than having "solutions" to problems, we believe that solutions vary from case to case, depending on environmental factors and the personal preferences of the caregiver and patient. Furthermore, by giving caregivers a strategy, instead of an answer, we are building a skill which they can use when there are new changes in behavior.

Problem-solving also can clarify the nature of the problem. Sometimes caregivers will find that problems occur less frequently than they expected, or that particular problems do not bother them, rather it is the accumulation of stress. Sometimes record-keeping reveals that the patient's behavior is not stressful, instead the problem is the caregiver's interpretation of it.

Problems may symbolize to caregivers the patient's disability or their own loss. The awareness that their intepretation of events actually increases the stress on themselves can lead to important changes in how they respond to the patient.

Support. Support includes emotional support for the primary caregiver, as well as identifying informal or formal helpers who can relieve the primary caregiver. Caregivers are more likely to turn first to relatives or friends for assistance, than to social agencies. Help can be provided in many ways, including staying with the patient, taking the patient out, housework, and transportation. Assistance from social agencies, such as housekeeping, a companion to sit with the patient, day care, and respite care, can make the caregiver's task a lot easier. These services, however, are not consistently available.

In many cases, however, support is available, but the caregiver is reluctant to ask for help. Many caregivers hold the belief that they should not have to ask for help, because they should be able to provide all the care themselves. Other caregivers believe that their family or friends should know what help they need, and they should not have to ask. Still others think that asking for help is too much of an imposition on others, or that no one else would be able to care for the patient. When caregivers are having trouble asking for help, their specific beliefs can be identified, and then alternatives proposed. For example, when caregivers feel they have to do everything themselves, it can be pointed out that unless they take care of themselves by getting help when they need it, they will become exhausted and be unable to continue providing care. The timing and phrasing of alternative

beliefs is crucial, and depends on the client feeling supported and understood.

Treatment Modalities

One-to-one Counseling. When a caregiver has not received assistance before, we generally prefer beginning with one-to-one counseling. At the time they seek help, caregivers are often under a good deal of stress and need individual attention. They may have a lot of questions, and need time to sort through the information. One of the most important elements is finding someone they can talk to who understands them and what they are going through.

The counselor begins the one-to-one counseling by answering questions the caregiver has about the disease, and then proceeds to issues of problem-solving and support. Some caregivers utilize the interventions effectively, and make significant improvements in their situations in only a few sessions. Others are not effective problem-solvers themselves, and require more time to learn how to make changes in their situation. In these cases, the counselor needs the skills of a well-trained psychotherapist, working in a collaborative way with the caregiver to overcome those cognitive, affective or behavioral problems that are interfering with adopting more effective caregiving strategies. It should be pointed out that the goals of interventions need to be the caregiver's, and the role of the counselor is as a facilitator, helping to overcome obstacles to those goals.

Family Meetings. Family meetings often result in impressive changes, by involving more people in caring for the patient and supporting the caregiver.

In many cases, one-to-one counseling proceeds well for awhile, but then comes to a standstill at the point at which the caregiver seeks more support. Because the amount of burden caregivers experience is related to the support tey receive from family and friends, the family meeting is an appropriate intervention that can directly lower the stress on them.

Family meetings often recapitulate the course of the one-to-one counseling. The first steps involve answering questions about the disease and correcting any misunderstandings. Then, when family members better understand what the patient and caregiver are going through, they can be encouraged to use their own problem-solving skills for giving more support.

As in the one-to-one counseling, families vary in their response to the family meeting. Some are able to use information readily, and propose useful strategies for helping the patient. Others may have long-standing conflicts among one another and with the caregiver. In those cases, it is important to focus on understanding the immediate problems caused by the dementia, rather than trying to resolve past differences. This problem-solving focus will sometimes be effective when there are long-standing conflicts. Needless to say, the counselor convening the family meeting should know about these conflicts in advance, and be ready to direct the family toward the caregiver's situation.

Support Groups. Support groups are the most popular program for caregivers, and are now available in most communities. These groups have many unique benefits, including creating the opportunity for caregivers to share information with one another and to understand their own experience better. Furthermore, problem-solving and support take on new dimensions in a group.

With respect to problem-solving, caregivers offer suggestions based on their own experiences which are often quite creative. Furthermore, some caregivers will not try something new if proposed by a counselor, but will take another caregiver's suggestion. They also learn by observing each other. When caregivers are worried about bringing in outside help, or using services such as day care, hearing about the experience of others can overcome their reluctance. They also develop the sense of helping and being helped by one another.

Although some groups admit caregivers without any prior screening, we generally prefer to involve the caregiver in one-to-one counseling first, both to provide more focused attention, and to determine if they would fit in a group. Support groups appear most useful to build upon and maintain the gains made in one-to-one counseling and family meetings.

Another issue is the role of the leaders. We believe that leaders need some background in understanding group process, so that therapeutic norms are established. Important issues for leaders include confidentiality, being non-judgmental of one another, giving everyone a chance to talk, not allowing one person to dominate the conversation, and not engaging in side conversations when someone else is talking. It is also important to respond when a group member cries or gets upset, or is disruptive to other participants.

Summary

This paper considers interventions with caregivers of dementia patients, which are designed to lower the burden they are experiencing, thereby making home

care a viable alternative. Intervention techniques include: providing information, teaching a problem-solving process, and support. Intervention modalities are one-to-one counseling, family meetings and support groups. Although dementing illnesses can have a devastating impact on the family, well-timed interventions are useful for helping caregivers adapt.

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